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ABSTRACT

This paper assesses federal legislation and programs affecting community-based services for independent living for people with disabilities. Independent living entitlement programs are contained in Title VII of the Rehabilitation Act of 1973, and include comprehensive services, centers for independent living, and independent living services for older blind individuals. Legislation also covers community-based services for persons with mental retardation and for persons with mental illness, and social security programs affecting all persons with disabilities. Federal programs have been created to develop independent living options for persons with severe disabilities, mental retardation, and mental illness. There is a need for additional independent living research, education, and professional training. Expenditures for long-term care facilities and services, intermediate care facilities, community-based residential facilities for mentally impaired individuals, and community-based independent living programs are analyzed, and the costs and benefits associated with community-based independent living services are noted. Recommendations are proposed for legislative amendments and revised funding support to promote the availability of community-based services for independent living. Forty-four references are listed. (JDD)

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TOPIC PAPER G:

COMMUNITY-BASED SERVICES FOR INDEPENDENT LIVING

National Council on the Handicapped

February, 1986

EC 211764

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This is one of a series of ten topic papers developed by the National Council on the Handicapped as part of its Special Report to the President and Congress: TOWARD INDEPENDENCE: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations. The members of the National Council on the Handicapped wish to expressly acknowledge with appreciation the special contribution made to this paper by Margaret A. Nosek.

TABLE OF CONTENTS

I. INTRODUCTION G-1

II. LEGISLATION G-6

A. Independent Living Legislation G-6
B. Legislation for Community-Based Services for Persons with Mental Retardation G-12
C. Legislation for Community-Based Services for Persons with Mental Illness G-13
D. Social Security Legislation Affecting All Persons with Disabilities G-14

III. INDEPENDENT LIVING FOR PERSONS WITH SEVERE DISABILITIES G-18

IV. INDEPENDENT LIVING FOR PERSONS WITH MENTAL RETARDATION G-23

V. INDEPENDENT LIVING FOR PERSONS WITH MENTAL ILLNESS G-26

VI. THE NEED FOR INDEPENDENT LIVING RESEARCH, EDUCATION AND TRAINING G-32

VII. EXPENDITURES, COSTS AND BENEFITS G-34

A. Expenditures G-34
B. Costs and Benefits of Community-Based Services for Independent Living G-41

VIII. RECOMMENDATIONS G-42

REFERENCES G-49

I. INTRODUCTION

Community-based services that promote independence for Americans with disabilities is a promising service delivery strategy for our nation. Environmental inaccessibility, overprotective and restrictive attitudes on the part of relatives and providers, lack of economic resources, ignorance of the concepts and techniques of independent living, lack of community based support services, and a bias toward institutions in current service-providing systems, however, restrict the ability of many persons with disabilities to achieve and maintain maximum independence. Billions of public dollars are currently spent on maintaining millions of disabled Americans in situations of unproductive dependency, which impose artificial limits on disabled individuals' potential to become contributing members of society. Significant savings will be realized as America moves toward becoming an accessible society, and as more severely disabled people become independent, contributing citizens.

The Council believes that the majority of persons with disabilities are able to sustain themselves and contribute to society provided that accessible facilities and services are available and they are assisted with overcoming the attitudes and barriers that unnecessarily restrict and prohibit them from attaining their goals for self-sufficiency and independence. Under ideal circumstances, many persons with disabilities can and do meet their own needs through their own self-sufficiency, and by relying, when needed, on relatives, friends, and private and public sources of assistance. When appropriate services and

assistance are available, few individuals with severe disabilities should be placed in institutions.

Independent living is defined in the National Policy for Persons with Disabilities (1983) as control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in the day-to-day life of the community in a manner of one's own choosing, fulfilling a range of social roles that includes productive work, and making decisions that lead to self-determination and minimize nonproductive physical and psychological dependence upon others. The independence defined here implies an optimally responsible and productive exercise of the power of choice. It implies that each disabled person, regardless of his or her mental or physical ability, should be encouraged and assisted to achieve maximum levels of quality of life, independence and productivity in the least restrictive environment and with due respect for cultural or subcultural affiliation.

Services to support independent living must be tailored to the needs of the individual. Persons with severe physical disabilities usually require assistance with personal care, domestic tasks, transportation, equipment maintenance, and modifications of home and work place for architectural accessibility. Those with sensory disabilities require reader and interpreter assistance with communication and expression. Persons with mental impairments who wish to live independently may require some assistance with cognitive tasks as provided by advocates. All

can benefit from information and referral about services and service providers, training in independent living skills, assistance in gaining mobility in the community, and individual advocacy. All who have extraordinary medical and personal care expenses require private and/or public resources to help cover such expenses. Those who are not employed usually require income maintenance support and financial assistance with daily living expenses.

Services for independent living include any formal or informal assistance that is needed by people with disabilities who are trying to increase control of their life, productivity, and participation in the community. Generally, these services are delivered by community-based organizations that are privately or publicly funded. However, services rendered by residential institutions can also be considered independent living services if they assist residents to achieve maximum independence in the least restrictive environment. In this sense, traditional long-term care service providers provide independent living services if they assist residents to reach their independent living goals.

Who can use community-based independent living support services? Almost all persons residing in private and government-operated institutions, regardless of the severity of their disability, could benefit in some way from independent living support services. For a large percentage, it could mean being able to live in the community in a residence and lifestyle of their own choice and with the opportunity to realize their potential for productive contributions to society. For those

with the most severe disabilities, it could mean receiving life support and enrichment services in a dignified and humane manner that maximizes their quality of life. Services for independent living could benefit those rejected by or who have failed in the vocational rehabilitation system. Potential beneficiaries also include the uncounted millions of disabled persons who live in rural areas and have little access to service providers of any kind, or who reside with families or in small group settings that restrict their ability to control their lives and reach their productive potential.

How many people could use independent living support services? In 1981, approximately 2,138,970 disabled persons were served in 38,975 residential facilities at a cost to the Federal and State government of $22.8 billion. These are totals of the following figures:

- o 499,169 persons with mental illness who were served in 277 State hospitals for $4.5 billion (Goldman, Gattozzi, & Taube, 1981),
- o 243,669 persons with mental retardation who were served in 15,633 residential facilities for $5.9 billion (Smith, 1984),
- o 1,396,132 elderly and physically disabled persons who resided in 23,065 nursing homes (Sirrocco, 1983) and other long-term care facilities at a cost to Medicaid of $12.4 billion (National Study Group on State Medicaid Strategies, 1983).

In 1984, State vocational rehabilitation agencies closed

131,572 cases which had not reached their rehabilitation goals. Out of almost 600,000 applicants, 245,435 were rejected as ineligible. Another 48,372 applicants were placed in the category of extended evaluation; that is, they were not rejected, but were not yet found to be eligible or ineligible for vocational rehabilitation services (Department of Education, 1985). Although there may be some overlap between these figures and the number of people in residential facilities, the total number of persons who sought disability-related services and who could extensively use independent living support services is probably more than 2.5 million.

II. LEGISLATION

Following is a description of legislation which has given rise to and supported community-based services for independent living.

A. Independent Living Legislation

Dalrymple and Richards (1983) gave a thorough analysis of the development and state of implementation of the key piece of legislation underlying the expansion of the independent living movement. Since 1920, a Federal/State rehabilitation program has existed to provide services to disabled people who could demonstrate immediately achievable vocational goals (PL 66-236). The program was amended in the 1960's to authorize a vocational evaluation period of up to 18 months. As a result of this extended evaluation clause, many previously excluded disabled people were able to obtain services from vocational rehabilitation which enhanced their abilities to live independently; however, if they were not vocationally ready at the end of the evaluation period, they were dropped from the rehabilitation program.

In the next few years, proponents of the independent living movement--including disabled individuals and their family members, rehabilitation professionals, health professionals, policy makers, and other advocates--lobbied for changes in the Federal/ State rehabilitation program. In particular, they urged changes in two respects: one, elimination of the requirement of vocational potential, and two, greater involvement of disabled people in developing policy for the program (Lorenz, 1982).

In the 1970's, legislation authorizing provisions of

independent living services without requiring a vocational goal was passed by Congress but received a presidential veto. A substantial achievement was made in 1973, however, when funds for a Comprehensive Needs Study were authorized by Congress to establish five research and demonstration projects to provide independent living services. Finally, in 1978, independent living legislation was passed which did not require vocational potential as a requirement for participation. However, this took form as a separate title of the Act and not as an amendment changing the focus of the existing vocational rehabilitation program for which the independent living supporters had hoped.

This independent living entitlement, which is Title VII of the Rehabilitation Act, contains three sections of current interest. Following is a summary of these sections and an assessment of the extent to which each section has been fulfilled to date.

1. Part A. Comprehensive Services. The purpose of this title is to authorize grants to assist States in providing comprehensive services for independent living designed to meet the current and future needs of individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from vocational rehabilitation services which will enable them to live and function independently (Rehabilitation Act, 1984). States are thus authorized to provide comprehensive independent living services, including traditional services such as vocational counseling, physical rehabilitation, orthotics and posthetics, and non-

traditional services, such as health maintenance, recreational activities, services for children, and housing modification. The scope of service provision appears to be from birth to death. An especially notable requirement of Part A is that disabled consumers have a substantial role in developing the State's plan of service. States are also required to give assurances in their State plans that no less than 20% of the funds received by a State under Part A will be used to make grants to local public agencies and to private nonprofit organizations for the conduct of independent living services (unless a waiver of this requirement is obtained from the Commissioner of the Rehabilitation Services Administration).

Fulfillment: To date, $5 million have been appropriated by Congress to implement Part A. It should be noted that versions of the Part A program (independent living services without vocational requirements) are presently being operated by State agencies for mentally disabled people, visually disabled people, and hearing impaired people.

For people with mental impairments, State mental health and mental retardation agencies nationwide have been given authority and substantial funding to carry out community programs to facilitate independent living for mentally retarded and mentally ill people. Some programs for this disability group have been developed by combining Housing and Urban Development loan/subsidy housing programs with operating funds from combined State funds and Federal income support sources such as Social Security Disability Insurance and Supplemental Security Income. In addition, community mental health centers provide a wide range of

services for mentally disabled persons, including counseling, day programs, and, frequently, housing and supportive services. One missing element, however, though, appears to be an extensive goal-oriented case management coordination system like the one found within vocational rehabilitation agencies.

Many State agencies for blind individuals have independent living programs that include independent living coordinators along with mobility and homemaker specialists. More States are beginning to establish councils for people with hearing impairments. While these programs do not limit service advocacy and provision to those people with vocational goals, they are frequently small programs with limited staffing and few direct services.

Physically disabled people without apparent vocational potential, however, are still ineligible to receive federally-funded services from State vocational rehabilitation agencies. Recently, a few State legislatures have authorized the use of State funds to provide certain independent living services, including attendant care, peer counseling, independent living skills training, and others. Among these States are Texas, California, New York, Massachusetts, Maine, North Carolina, Ohio, Minnesota, and Wisconsin.

2. Part B. Centers for Independent Living. This part authorizes grants to establish independent living programs and requires substantial involvement of disabled people in policy direction, management, and employment within the independent living program. The general intent of Part B is provision of

services that are multiple and comprehensive, such as intake counseling, advocacy, independent living skills training, housing and transportation, referral and assistance, health maintenance, peer counseling, education and training, recreation, attendant care, and others.

Fulfillment: In Fiscal Year 1979, $2 million was appropriated for Part B, funding only ten grants. Subsequent appropriations were $15 million for Fiscal Year 1980, $18 million for Fiscal Year 1981, and $17.28 million for the Fiscal Year ending September 1983, expanded to $19.4 million by continuing resolution and maintained at that level for 1984. Appropriations for 1985 are $22 million. Altogether, more than 159 programs are being at least partially supported by these funds.

For the most part, grant awards were made to State vocational rehabilitation agencies that subcontracted with community-based organizations which had boards largely composed of disabled persons. There are a small number of variations on this pattern. For instance, a small number of grant awards were made to local organizations when State agencies chose not to apply. Also, in a few instances, State agencies chose to operate independent living programs themselves, fulfilling the requirement of substantial consumer involvement in policy direction by setting up advisory boards of disabled persons.

The most comprehensive analysis to date of the full range of independent living programs has been done by the Independent Living Research Utilization Project. They have identified 281 programs which deliver independent living support services (ILRU Directory, 1985). Their 1983 survey of these programs produced

significant data (ILRU Registry, 1984; Veerkamp, 1984). Of the 157 programs responding to the survey, 63% met the criteria for an independent living center, including being consumer-controlled and community-based. The average profile of a program's budget was 79% Federal and State funds, 4% local funds, 8% private agency or foundation funds, and 9% program generated funds (fees, memberships, etc.). Seventy percent of the programs served only persons in the immediate community, 15% served those in rural areas, and 13% served those in other cities around the State. The most prevalant disability types served were spinal cord injury (18%), blindness (16%), mental retardation (12%), and cerebral palsy (10%).

In the six years since Title VII was incorporated into the Rehabilitation Act, independent living centers have developed the experience needed to establish realistic operating standrds and policies. They have also matured to the stage of being able to sustain a national organization. National standards that will assure that quality services standards are provided by all independent living centers receiving Federal funding were approved by the National Council on the Handicapped in 1983. This is an important step in establishing independent living centers as a reliable source of quality services that help persons with severe disabilities to achieve their goals for self-sufficiency. A destabilizing factor is the absence of core funding for these centers. From year to year, each center does not know the amount of funding it will receive from the Federal Government (if any) during the coming year for funding. Given

the relatively limited funding available, this frequent reapplication process diverts energy from improving community resources and service delivery. In addition, the absence of a reliable funding source makes it difficult for the centers to firmly establish themselves within the service delivery community and to compete as successfully as they might for other sources of funding. Over the long run, successful centers must obtain funding from a range of public and private sources. For this reason, they should actively involve private business and other community leaders in their planning and fundraising processes.

3. Part C. Independent Living Services for Older Blind Individuals. This part authorizes grants to States to provide independent living services to persons 55 years of age or older whose visual impairment makes employment difficult to attain but for whom independent living goals are possible. However, these individuals should be able to receive services under Part A and from independent living centers funded under Part B.

Fulfillment: No appropriations have been made for Part C. For the Fiscal Year 1986 Budget, the House has recommended a funding level of $5 million.

B. Legislation for Community-based Services for Persons with Mental Retardation.

Conley and Noble (1985) have analyzed legislation relevant to the move toward community-based services for persons with mental retardation. In 1971, the Intermediate Care Facilities for Mentally Retarded Persons (ICF/MR) program was enacted, primarily to improve the quality of care being provided in State institutions. Almost from the beginning, however, the program

was used to support some community residential programs. In 1976, the Social Security Act was amended to permit Supplemental Security Income (SSI) payments to be made to public residential facilities with 16 or fewer residents. Previously, SSI payments could not be made to residents in public facilities. In 1981, Title XIX of the Social Security Act was further amended to allow the Secretary of the Department of Health and Human Services to grant waivers to States to use Medicaid funds to pay for non-medical services to elderly and disabled persons who would otherwise require institutional care. The Home and Community-Based Waivers Program was explicitly designed to promote the development and provision of community-based care.

C. Legislation for Community-based Services for Persons with Mental Illness

Federal funding of services for persons with mental illness is authorized largely by the same legislation as services for mentally retarded persons, that is, Titles XVIII, XIX, and XX of the Social Security Act. Prior to 1981, federally-funded community mental health centers (CMHCs) were funded in part through National Institute of Mental Health (NIMH)-initiated categorical grants to the individual CMHCs. With the initiation of the Alcohol, Drug Abuse, and Mental Health Services Block Grant to the States, NIMH no longer monitored formerly federally-funded CMHCs. Instead, NIMH reclassified these organizations into other organization types according to the types of services they directly controlled and administered. As a result of this reclassification, most organizations formerly classified as federally-funded CMHCs were reclassified as freestanding

psychiatric outpatient clinics, non-Federal general hospital psychiatric services, and multiservice mental health organizations. The term "community mental health center" is no longer used (Manderschied, Witkin, & Bethel, 1985).

D. Social Security Legislation Affecting All Persons with Disabilities

A major portion of the resources which support persons with severe disabilities of all ages in institutional settings comes from the Social Security Act. While other provisions of this Act enable people to receive a variety of social services and income support benefits, strict eligibility requirements regarding income and the involvement of medical professionals in the delivery of services hinder the ability of beneficiaries with disabilities to live independently in community settings.

Many problems and inadequacies exist within the Social Security system for persons with disabilities. Attendant services are not readily available to those who need it. Funds for this service are generally very limited and eligibility is very strict. There is a general lack of comprehensive case management assistance for independent living, including transition services from the hospital to the home, institution to community, and from parents' home to independence in the community and little assistance in equipment selection and maintenance and in locating sources for other independent living support services. The legislation does not authorize enough funding for education and training for independent living or for assistive devices. Habilitative and rehabilitative training, including prevocational services, are often not available under

Medicaid or Medicare funding. There is no comprehensive medical insurance for disabled persons who are unable to obtain adequate insurance through their employer or who are ineligible for other Federal medical benefits.

Specifically, the following provisions in the Social Security Act relate to independent living for persons with disabilities:

1. Title II: Old Age and Surviving Dependents Insurance. Medicare eligibility currently terminates for disabled beneficiaries who engage in substantial gainful activity, despite continuing disabilities.

2. Title V: Maternal and Child Health/Crippled Children Services. Discretionary funds under this title could be available to demonstrate the value of attendant services for adolescents to achieve peer integration and independence, and to encourage States to provide attendant services and other in-home support services in order to reduce hospitalization.

3. Title XVI: Supplemental Security Income. SSI benefits for disabled beneficiaries who require some attendant services are the same as for those who do not require attendant services, even though the former can have considerably higher living expenses. Veterans Administration legislation has provisions for extra funding for "essential persons" who provide valuable personal assistance to the beneficiary with a disability. Such supplementary benefits are also not available from States.

Under current law, an individual with a disability who stops working for disability-related reasons and becomes

eligible for Social Security Disability Insurance (SSDI) will have no medical insurance for two years due to the Medicare wait period, unless they are financially capable of converting any prior coverage to an individual plan. Because persons who work generally have assets in excess of $1,500, the cannot qualify for SSI or Medicaid. Conversely, persons who receive SSDI or SSI also receive medical benefits which can rarely be matched by private insurers if they choose to attempt a return to work. Section 1619 (a) and (b) is a demonstration project which attempts to remediate this problem for those who receive SSI by allowing them to continue receiving Medicaid benefits despite engaging in substantial gainful activity.

4. Title XVIII: Medicare. Certain independent living support services are available only to those who are considered "home bound," and these services must be supervised and sometimes provided by skilled nurses. Personal assistance (attendant services) and other in-home support services are available only to persons leaving hospitals or extended care facilities on a very short time-limited basis. For applicants for Medicare benefits, there is a two year wait period.

5. Title XIX: Mediciaid. Attendant services are sometimes available but not mandatory under State Medicaid plans. The income limit for the "medically needy" category is 133% of the AFDC level instead of the SSI level, which is higher. Independent living centers are not currently included as eligible providers under this funding. Medicaid-funded services must be delivered in the beneficiary's "own home," thus limiting

participation in community activiites.

6. Title XX: Social Services Block Grant. Independent living services receive very little, if any, funding under this title even though the title's purpose is to enhance life in the community.

III. INDEPENDENT LIVING FOR PERSONS WITH SEVERE DISABILITIES

Prior to the independent living movement, traditional services for persons with severe disabilities emphasized medical recovery and employability as the major indicators of success. This narrow focus relegated a large population of persons with disabilities to the limited life options of institutional placement or extensive dependence on family care. The potential for recovery or employment and the ability of people with disabilities to live independently in the community either were not recognized or were grossly underestimated by the rehabilitation and social service systems. In response to the inherent injustice of this situation, independent living training and support services began to be delivered by traditional providers and new entities called independent living programs.

Conceptually, "independent living program" is generic--the most broadly defined term relating to organizations that work with disabled individuals who wish to live independently. Several different kinds of independent living programs exist. They differ from one another in at least six primary areas: the service setting may range from residential to nonresidential; the service delivery method may range from direct to indirect, or a combination of both; the service delivery style may range from professional to consumer; the vocational emphasis may range from primary to incidental; the goal orientation may range from transitional to ongoing; and the disability type served may range from single to many. The features of the independent living program are determined by the needs of the consumers

served, the availability of existing community resources, the physical and social make-up of the community, and the goals of the program itself. Custodial care facilities and primary medical care facilities are specifically excluded from the definition of an independent living program.

The development of independent living centers and the independent living movement began about 15 years ago. The movement was initiated primarily by young adults with physical disabilities who sought to broaden the approaches and services available to them so that they might acquire the knowledge, skills, confidence, and assistance they needed in order to participate more fully in society. The practice of delivering independent living support services to disabled persons by disabled persons combined with advocacy for community accessibility had its start in Berkeley in the early 1970's. The Berkeley Center for Independent Living (Zukas, 1975) and the Boston Center for Independent Living (Fay, 1977) became models for the delivery of these services.

The philosophical foundations of the independent living movement and its impact on individuals and community life as demonstrated by these early programs were documented by Pflueger (1977) and DeJong (1979). DeJong set out three major propositions that underlie the philosophical context of the community-based independent living movement:

- Consumer Sovereignty--disabled persons, the actual consumers of the services, not professionals, are the best judges of their own interests. They should ultimately determine how services should be organized on their behalf.

- Self-Reliance--disabled persons must rely primarily on their own resources and ingenuity to acquire the rights and benefits to which they are entitled.
- Political and Economic Rights--disabled persons are led to participate fully and freely in the political and economic life of the community.

The centers for independent living in Berkeley and Boston established the model upon which independent living legislation is based. This model has been defined by Frieden et al. (1979) as a community-based, nonprofit, nonresidential program which is controlled by the disabled consumers it serves, and provides directly or coordinates indirectly through referral those services which assist severely disabled individuals to increase personal self-determination and to minimize unnecessary dependence upon others. The minimum set of services provided by an independent living center include housing assistance; referral of attendants, readers, and/or interpreters; peer counseling, financial and legal advocacy; and community awareness and barrier removal programs. Other services that are either provided or coordinated by independent living centers include transportation provision or registry, peer counseling, advocacy or political action, independent living skills training, equipment maintenance and repair, and social-recreational services.

In 1978, Congress authorized direct support of independent living programs as part of the discretionary programs of the Rehabilitation Services Administration (RSA). The Rehabilitation Act of 1973 was amended to add Title VII--Comprehensive Services for Independent Living. As expressed in the legislation, Title VII was intended to assist in development of community-based

service centers to provide information and referral, transportation, attendent care, peer counseling, skills training, and other services. The goal was to facilitate the integration of severely disabled adults into the mainstream of community social and economic life, i.e., to decrease their dependence and increase their self-determination and ability to be productive, contributing members of society.

Title VII authorization drew upon the program development experience of early independent living centers and led to the substantial growth of independent living centers across the country. Using an approach that philosophically and operationally differs from those of more traditional service systems, the independent living centers actively developed and implemented needed programs to facilitate increased independence for the people they sought to serve.

In short, the impetus and strength of the independent living movement resulted in a viable service alternative that: 1. emphasized consumer sovereignty, self-reliance, and economic and political rights; 2. resisted approaches that put the onus of the problem on the consumer and left decisions about service in the hands of the professional; and 3. resisted the use of assessment systems that were experienced as paternalistic. The hallmark of the independent living movement is advocacy for change on both the individual and community level.

As a policy issue, independent living has only recently been examined (Galvin, 1980; Siegman, 1980; Dalrymple & Richards, 1984). In 1983, the concepts of independent living were incorporated into the National Policy for Persons with

Disabilities by the National Council on the Handicapped. This was the first policy document to actively apply the concepts of independent living to all disability groups and call for an independent living orientation in the provision of all human services.

Very little has been written about independent living for populations underrepresented in programs funded under Title VII. Katz (1965), Braddock (1978) and Sigelman and Parham (1981) looked at independent living and mentally retarded persons. Other populations examined include persons who are deaf (Petal, 1980), elderly (Williams, 1981), and learning disabled (Brown, 1984), and who live in rural areas (Richards et al., 1984; Richards, in press). For persons with mental impairments the key focus has been movement from large institutions to smaller community-based settings. A discussion of this parallel trend to the independent living movement follows.

IV. INDEPENDENT LIVING FOR PERSONS WITH MENTAL RETARDATION

The needs and potential of persons with mental retardation have been thoroughly researched and documented. The system for providing these persons with services is the most extensive and well funded in the field of disability. It consists of an intricate continuum of living arrangements, including multipurpose long-term care institutions, special purpose institutions, intermediate care institutions, a range of group homes and boarding homes for sheltered care, foster homes, and private homes (Braddock, 1978). However, only a portion of this system could qualify as independent living support services according to the above definition.

Sigelman and Parham (1981) cite the decrease in public residential facility populations and the increase in the number of smaller and more homelike community residential facilities as a move toward independent living support services for persons with mental retardation. They claim that the only common denominator of these facilities is the provision of a place to live and supervision; otherwise they differ widely in size, training goals, level of funding, and so on. In a national survey, O'Connor (1976) was able to identify 611 community residential facilities for developmentally disabled persons, most only recently opened. Using a somewhat less restrictive definition of a community residential facility--excluding only family care and foster care arrangements, facilities not licensed or contracted as mental retardation service providers, and apartment programs with no live-in staff--a more recent national

survey uncovered 4,427 community-based residential facilities serving a total population of 76,250 (Bruininks, Hauber, Kudla, 1980). Over half of the facilities had opened between January 1973 and the time of the survey in June 1977.

Clearly, then, the deinstitutionalization movement has made rapid progress, and community residential facilities today represent a major option for many retarded persons who could not easily live on their own. According to the survey of Bruininks et al. (1980), approximately a third of the residents came to their facilities from institutions, but almost as many (32.4%) came from their natural homes. The remainder had entered their community residential facilities from other residential settings. These findings indicate that such facilities are also meeting needs among persons who, while never institutionalized, require more training and support than their own families can provide, especially when they reach adulthood.

About 62% of the residents of community residential facilities are 22 years old or older (Bruininks, Hauber, and Kudla, 1980), and the vast majority are in some productive activity in their communities. According to O'Connor's 1976 survey of community residential facilities, about 9% of the residents were competitively employed; 48% were in workshops or training programs; 31% were in school; and 8% were in some other major day activity. Only four percent were without such major activities. These individuals, then, are active in the community and yet display widely different degrees of competency. Moreover, residents are drawing on the whole range of services available in the community, for it would be contrary to the

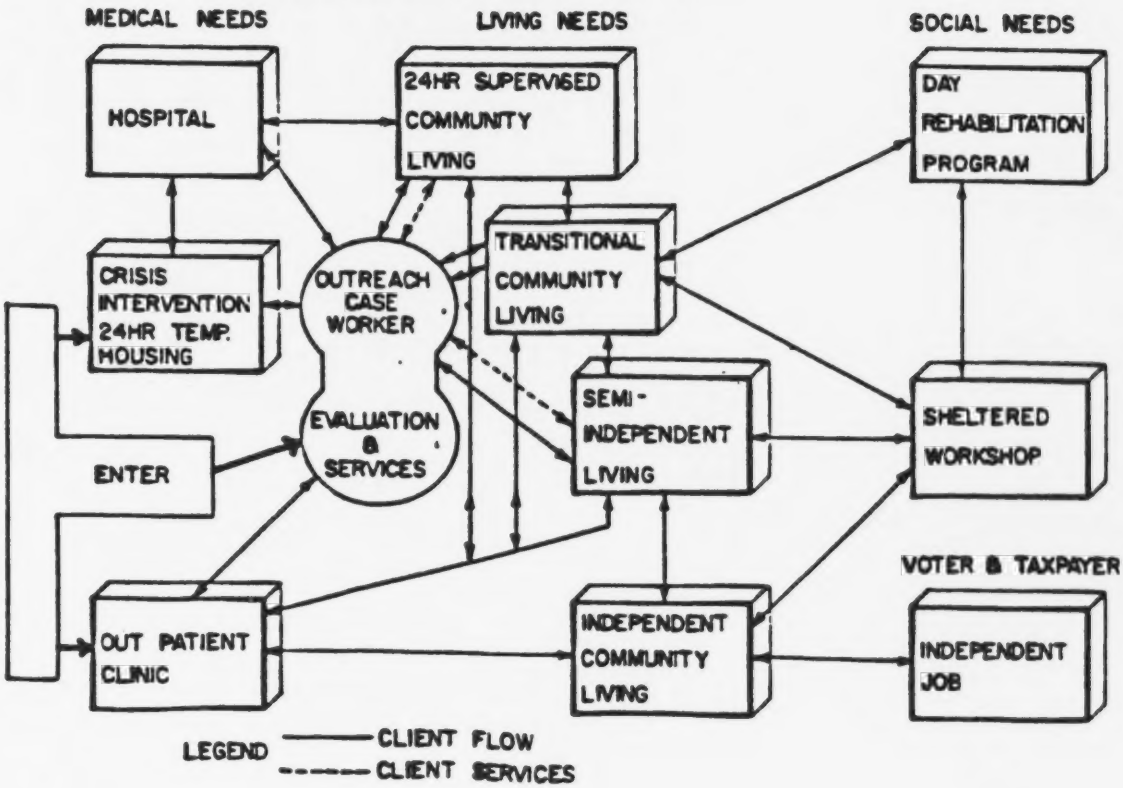
purpose of small, homelike facilities to have all services provided in-house as they are in large institutions (Sigelman & Parham, 1981).

V. INDEPENDENT LIVING FOR PERSONS WITH MENTAL ILLNESS

In the interval between 1970 and 1982, several changes have taken place in the number of organizations constituting the nation's organized specialty mental health service delivery system. The total number of organizations that provide mental health services rose from 3,005 to 4,302 between 1970 and 1982, an increase of 43 percent. Despite the increase for all organizations combined, the number of State and county mental hospitals decreased from 310 to 277 in the same time period. Represented in these total figures are private psychiatric hospitals, non-Federal general hospitals with separate psychiatric services, residential treatment centers for emotionally disturbed children, and freestanding psychiatric outpatient clinics. Within specialty mental health organizations, a variety of different types of services are provided. Among the principal services are inpatient, outpatient, and day treatment care (Manderscheid et al, 1985).

As diagrammed on the next page by the Texas Alliance for the Mentally Ill, the full spectrum of service needs for this population includes far more than inpatient, outpatient, and day treatment care. Dramatic pharmacological, social, and legal changes have shaped community living programs for persons with chronic mental illness. In the 1950's, a revolution in the care of these individuals was made possible by the discovery of antipsychotic medications, under which previously disoriented persons demonstrated a renewed capacity to care for themselves. This, then, set the stage for the possibility of community care

TEXAMI PLAN FOR MEETING NEEDS OF CHRONICALLY MENTALLY ILL



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for persons who had been receiving only minimal care in large public hospitals.

About the deficits of the traditional large public psychiatric hospitals there was considerable agreement: they were too large, limited by a universal medical model, and functioned as a closed society--isolated, like a penitentiary, from society at large. Community residences, by contrast, were to be small, family-modeled living arrangements, functioning as open social systems, which existed within, rather than isolated from, the community. These new facilities survived and began to proliferate. In 1960, there were only seven professionally conceived programs in the entire country; by 1973 there were 209; and there are many more now.

The proliferation of these models has been given enormous impetus by court decisions of the 1970's. In addition, the large institutions, the local communities, and the State governments have all been affected by these judicial decisions. A tragic irony, however, is that these judgments in the name of patients' rights too often had the effect of forcing many patients into the community before adequate rehabilitative facilities were there to receive them (Budson, 1979).

In the space of three decades, powerful medical, social, and legal forces have moved the locus of treatment for persons with severe mental illness from the state hospital to the community. Attempts to reform the old custodial system have produced in their turn a complex and often contradictory set of demands that these people not be incarcerated without treatment; that these people not be released into the community before adequate

community care programs exist; that large, expensive institutions not continue to drain dwindling State coffers; that unscrupulous private enterpreneurs not victimize again the vulnerable population of discharged patients (Budson, 1979).

The past decade of intensive development has, indeed, produced a broader spectrum of community care facilities. These facilities vary not only in function and philosophy, but often, unfortunately, in quality of care as well. At least ten different types of housing are currently in use in the United States: 1) transitional halfway houses; 2) long-term group residences; 3) cooperative apartments (satellite housing, landlord supervised apartments, post-halfway house accommodations); 4) lodge programs; 5) total rural environments (work camps); 6) foster care (family care); 7) crisis centers; 8) nursing homes; 9) board-and-care homes; and 10) hotels.

The National Institute of Mental Health has defined the transitional halfway house as a "residential facility in operation seven days a week with round the clock supervision (often a staff member living on the premises) and providing room, board, and assistance in the activities of daily living." Non-profit, private corporations usually operate these facilities in large old houses with 15-20 residents who generally participate daily in a planned program outside the dwelling.

Although the long-term group residence resembles the transitional halfway house in many particulars, its residents are usually sufficiently lacking in living skills, or sufficiently symptomatic, to require a higher onsite

staff/resident ratio.

Cooperative apartments are distinctive in that they have no onsite staff and are usually comprised of groups of two to four per unit. There is a regular staff visit from the sponsoring mental health agency to oversee the living arrangement as well as the required outside daily program. Cooperative apartments are often developed as outward community extensions or satellites of staffed residential programs.

Total rural environments are nonhospital residential facilities which offer total supervised living including daily on-premises farming chores. The focus is that of an operational farm which provides ongoing reality-based responsibilities with high attention to the fulfillment of rehabilitative goals.

Foster or family care, one of the oldest community placements, entails the location of ex-patients in private homes. Up to four residents may be placed in one foster home. The individual is supervised by the family caretaker who is in turn supervised by a visiting social worker from the referring institution.

Nursing homes are a major community residential site to which thousands of chronically mentally ill persons who are elderly or physically handicapped are sent. The nursing home was one type of supervised residential facility which was readily available when the pressure to discharge patients mounted.

A "crisis center" is an alternative residential facility which allows the individual to leave a noxious home situation without having to go to a psychiatric hospital. Such a facility has a higher staff/patient ratio, is small, and has a capacity

for around-the-clock care.

Board-and-care homes have been the recipient of uncounted numbers of discharged chronic patients. Their use has stimulated much controversy. These are generally proprietary rooming houses which provide a wide range of care, depending upon the interest and motivation of the proprietor (Budson, 1979).

Although the range of living options for persons with mental illness appears to be broader than that available to persons of different disability groups, it is in fact very limited. Eligibility for residence in certain facilities is restricted to those recently in larger institutions, in effect requiring hospitalization prior to community living. Many facilities will not accept persons who have visual, hearing, or mobility impairments in addition to mental illness due to a lack of personal assistants (readers, interpreters, attendants), and architectural inaccessibility. Availibility of space in any of these options, let alone those with progressive, independence oriented programs, is grossly inadequate given the enormity of the population in need.

VI. THE NEED FOR INDEPENDENT LIVING RESEARCH, EDUCATION, AND PROFRESSIONAL TRANINING

There is general concensus that training for independent living must begin as soon as all children first enter school. For children with disabilities, special independence-oriented education should start from birth to counteract the effects of negative attitudes toward disability and other barriers in society. Education systems should be required to give all students the opportunity to understand the reality of disability and the abilities of persons with disabilities. This will prepare everyone for the inevitable onset of disability at some point in their life and help eradicate barriers to equal opportunity.

If such education is to be offered to the general public with specialized education offered to persons with disabilities and their families, curricula must be developed and specialists in this area must be trained. Pre-service training for professionals in education, medicine, and other disability-related fields should be required to include the study of independent living needs of children and adults with disabilities.

The quality of training for the professionals who will strongly influence the lives of persons with disabilities will reflect the state of the art in research related to independent living. Currently, the state of the art in this area is embryonic. Independent living services have for the most part responded to the constraints imposed by existing systems, and have been developed by trial and error. Very little empirical,

valid research underlies the provision of community-based services for independent living. Most current research supports services for mental impairment rather than for physical impairment.

At the present time, two research and training centers in independent living are funded by the National Institute for Handicapped Research. Some grants have been given by the Rehabilitation Services Administration to improve the delivery of services by centers for independent living, and by the Office of Special Education to develop curricula for independent living skills training as part of the transition from school to work and life in the community. However, these efforts are miniscule compared to the grant potential within the Department of Education.

There must be a better understanding through controlled research and development activities of what independence is and how the independence of persons with disabilities can be developed and enhanced. There should be ongoing scientific efforts to gather and analyze data on the independent living needs of the disabled population; to evaluate methods for meeting those needs; to provide technical assistance to providers of independent living support services and those who wish to initiate such services; and to explore and demonstrate innovative methods, including the use of technology, for delivering independent living services and living independently for persons with all types of disabilities.

VII. EXPENDITURES, COSTS AND BENEFITS

In analyzing current expenditures for independent living and what has been called long term care services, it is necessary to consider the expense of not providing independent living support services, i.e. institutionalization, as well as the expense of operating community-based programs. Following is a discussion of expenditures for long term care facilities and services, intermediate care facilities, community-based residential facilities for mentally impaired individuals, and community-based independent living programs. It is followed by a discussion of the costs and benefits associated with community-based independent living services.

A. Expenditures

It is difficult to estimate total public and private expenditures for long term care services. According to the National Study Group on State Medicaid Strategies (1983), about 60 to 80% of elderly people's long term care is provided by friends, neighbors, and relatives, with no remuneration. This figure is probably equally applicable to younger disabled persons. The primary source of public expenditures for long term care is Medicaid, which in 1981 accounted for $12.4 billion, or 81% of public long term care expenditures. The bulk of public and private long term care expenditures pays for nursing home care, which is the third largest and one of the fastest growing areas of national health expenditures. Between 1965 and 1978, the growth in nursing home expenditures averaged 16.9% per year, increasing from $2.1 billion to almost $16 billion. (Of the 1978

total, 53% came from public and 47% from private funds, mostly out of pocket payments.) This figure is expected to double in 1985 and reach $76 billion by 1990 (Freeland, Calat, and Schendler, 1980). The National Center on Health Statistics data show that 12.6% or more than 174,000 of the residents in nursing homes are under age 65 (Sirrocco, 1985).

Medicaid financing paid primarily for skilled nursing and intermediate care facilities in 1981 ($12.3 billion). Of this amount, just $146 million or 1.2% was spent on home health care, primarily in New York and California. Medicaid skilled nursing facility and intermediate care facility payments have grown at an alarming rate. In response to rising institutional care costs, Congress -- in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 -- authorized waivers to allow State Medicaid programs to expand the provision of home and community-based services as an alternative to institutional care. Because these initiatives are just beginning, they are not reflected in expenditure data or budget projections. A small but growing category of Medicare reimbursements covers some post-hospital nursing care as well as home health visits.

Other public long term care funding is available from the Veterans Administration and under the Older Americans Act, Title XX of the Social Security Act, and the Housing Act of 1959. (Title XX long term care expenditures are no longer separately measureable because of the 1981 conversion to block grant funding.) Another source of Federal and State financing is SSI supplemental payments for domiciliary and other residential care facilities.

The Title XIX Immediate Care Facilities For the Mentally Retarded (ICF/MR) program is the major Federal source of funding for both institutional and community care of persons with mental retardation. In Fiscal Year 1985, it accounted for 34.2% of a total of $7.773 billion in Federal spending for mentally retarded and developmentally disabled persons (Braddock, Hemp & Howes, 1985). To gain perspective on the significance of Social Security as a source of revenue, it is useful to observe that of the total Federal expenditures in the area of mental retardation in Fiscal Year 1985, Supplemental Security Income (SSI) payments to persons with mental retardation constituted 19.7% of total Federal spending in this area in Fiscal Year 1985; Social Security Disability Insurance (SSDI), 16.4 %; noninstitutional Medicaid expenditures, 12%; and Title XX social services, 2.8%.

The growth of Federal reimbursements for institutional care of mentally retarded persons since 1977 has been explosive (Conley & Noble, 1985). The Federal share of expenditures for State institutional services has increased from 23% to 45%, rising from $570 million in 1977 to $1.9 billion in 1984. Although the Federal share of expenditures for community services increased significantly, from $45 million (6%) in 1977 to $663 million (21%) in 1984 today the amount spent on community services is less than a third that spent on institutional services.

According to Conley and Noble (1985), the Title XIX ICF/MR program has a strong institutional bias that is sometimes reinforced by funding arrangements between State and local

governments. Where local governments do not share in the cost of community-based services, there is a strong incentive to avoid developing community alternatives to institutional care for persons with mental retardation.

A compilation of all public funds spent for mentally retarded persons in 1981 was done by Smith (1984):

Total funding (in billions)		$11.7
Source of funds		
Federal	$5.4	
State	$6.3	
Expenditures		
Residential care		$5.9
institutions	$ 3.7	
community facilities	$ 0.7	
other long-term care	$ 1.1	
miscellaneous	$ 0.4	
Community-based support services		$4.5
SSI/SSDI and State grants to counties		$1.3

Smith further lists per diem estimates for various residential settings based on a report of the Department of Health and Human Services Inspector General in 1981:

ICF/MR (institution)	$80/day
ICF/MR (community)	$65/day
Non-ICF/MR group home	$50/day

These group homes are financed with the residents' SSI/SSDI payments, State funds, Section 202 loans and Section 8 rent supplements from the Department of Housing and Urban Development, food stamps, parent/resident fees, and voluntary sector contributions.

Wieck and Bruininks (1982) present a per diem reimbursement rate according to facility size categories. Public residential facilities with fewer than 500 residents reported the highest per

diem of $60.05. Lower per diems were reported for larger facilities: $41.68 for facilities with 500-999 residents, $47.81 for facilities with 1,000-1,599 residents, and $46.82 for facilities with more than 1,600 residents. In contrast, community residential facilities showed a steady progression in per diem rates, with the smallest facilities having the lowest per diem ($15.51) and the larger facilities reporting higher per diems ($25.09).

Size of Public Residential Facilities	Average Per Diem
<500	$60.05
500 - 999	41.68
1,000 - 1,5999	47.81
1,600+	46.82

Size of Community Residential Facility	Average Per Diem
1 - 5	$15.51
6 - 15	16.40
16 - 32	18.86
33 - 64	25.50
65+	25.09

In the area of mental health, expenditures for the provision of services rose dramatically in the 1970's. Frank and Kamlet (1984) discuss these expenditures in three categories according to the locus of mental health care:

- The specialty mental health care sector, which includes State mental hospitals; community mental health centers; office-based psychologists, psychiatrists, and social workers; and general hospital psychiatric units.
- The general medical sector, which includes psychiatric services in general hospitals outside of psychiatric units, nursing homes, and nonpsychiatrist physicians.
- The human service sector, which includes schools and the criminal justice system; and the nonhealth sector, which includes transportation services for treatment of mental disorders, expenditures by the Social Security Administration for the maintenance of mentally disabled individuals, and expenditures made under Title XX.

The estimated total direct costs for mental illness in 1980 were between $17.2 billion and $19.9 billion. When estimated transfer payments were added, the range was between $19.4 billion and $24.1 billion. The high estimate of direct costs represents 7.7% of total expenditures on health care for the nation in 1980 (Hodgson & Kopstein, 1984). These figures also imply that direct costs of mental health care comprised approximately 0.65% of the Gross National Product in 1980. The total direct costs were incurred as follows (Frank & Kamlet, 1984):

SECTOR	AMOUNT (billions)	PERCENT
Specialty mental health	$10.7	53.6
General health	$ 6.1	30.6
Human services and nonhealth sector	$ 3.1	15.8

Social Security Disability Insurance payments made to individuals with mental illness (excluding alcoholism, drug dependence, and alcoholic psychosis) in 1980 were estimated to total $1.8 billion based on data from a survey conducted in 1976. Applying a similar methodology for payments to spouses and children of mentally ill workers, a total figure for 1980 of $4,089 million is estimated.

The annual real rate of growth in direct costs of mental health care is estimated to be 1.7% between 1977 and 1980. Comparison with the rate of growth (3.6%) in the general health sector for direct costs of health care as a whole indicates that the real claims on resources made by the mental health sector are

decreasing relative to those made by all health care (Frank & Kamlet, 1984).

In contrast to the wealth of literature on spending in the areas of mental retardation and mental illness, studies of the cost of independent living services for all other disability groups are scant. The Rehabilitation Services Administration reported in 1983 that the $19.4 million appropriated under Title VII Part B funded in whole or in part 156 centers for independent living which delivered services to 26,000 severely disabled people, 69% of whom had physical disabilities.

It is clearly evident that funding for institutionalization of disabled people far outweighs funding for independent living. Even among the programs operated for mentally retarded and mentally ill persons which are established as community-based centers, few truly focus on maximizing self-determination and eliminating unnecessary dependence on others to the extent of one's potential. The question at hand, then, is not one of limited resources; it is one of orientation, priority reassessment, and funding reallocation to support community-based independent living services. When such services are in place, most persons currently living in institutions can be served in the community.

B. Costs/Benefits of Community-Based Services for Independent Living

Analysis of the economic benefits resulting from the availability of community-based services for independent living is extremely complex and confounded by the highly individualized nature of disability and personal support systems. The provision

of Federal funding for personal assistance, subsidized housing, and other support services does not guarantee that the individual will become gainfully employed and become a taxpayer instead of a tax-user. Indeed, under the present system, by becoming employed, individuals become ineligible for the benefits which made them employable. Yet economic benefits do exist. These are best illustrated by individual case studies:

> Mary had a stroke with moderate speech involvement and uses a walker. She receives SSI, Medicaid, subsidized housing benefits, food stamps, a utility subsidy, and weekly homemaker services which cost approximately per month. She uses a public paratransit system for mobility in the community; however she can rarely get reservations for the times she needs or wants to travel. Although Mary has a master's degree in social work, she is unable to secure employment due to doubts expressed by interviewers about her ability to communicate with clients. If employers were more aware of ways to tap Mary's abilities through job modifications and technology, and if reliable, accessible public transportation were more available, she could be earning a salary of $1,200 to $1,500 per month.

> James has lived in a State school for persons who are mentally retarded for 34 of his 40 years at an average cost to the Federal and State government of $2,400 per month. He has severe cerebral palsy and uses a power wheelchair. He also has a learning disability. James is outgoing and frequently participates in community advocacy activities. He spent a year in the transitional living house run by the local center for independent living. He now lives in the community in an apartment with two students referred to him by the center for independent living. They provide for his personal assistance and housekeeping needs. He receives an array of benefits similar to Mary's, valued at approximately $1,000 per month. Next fall, he hopes to be sponsored by the State rehabilitation agency to attend classes at the community college. He plans to obtain a high school equivalency degree and seek training and employment as a computer operator.

VIII. RECOMMENDATIONS

The Council has defined independent living as "control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities" (National Policy for Persons with Disabilities, 1983). Living independently includes managing one's affairs, participating in the day-to-day life of the community in a manner of one's own choosing, fulfilling a range of social roles including productive work, and making decisions that lead to self-determination. Community-based services that promote such independence for Americans with disabilities constitute one of the most promising service delivery strategies for our Nation.

The Council wishes to affirm that the independent living philosophy and a preference for community-based services should permeate the services and benefits supported by the Federal Government. The goal should be to establish core funding for a continuum of community-based services guided by independent living concepts.

In order to live independently, disabled persons require a wide range of support services according to their disability type. Persons with severe physical disabilities usually require assistance with personal care, domestic tasks, transportation, equipment maintenance, and modifications of home and work place for architectural accessibility. Those with sensory disabilities may require assistance with interpersonal communication such as that provided by readers and interpreters. Persons with mental impairments who wish to live independently may require some

degree of supervision and assistance with cognitive tasks. All persons with disabilities and their families can benefit from a single source of information and referral about services and service providers.

In 1978, Congress incorporated a program of Comprehensive Service for Independent Living in Title VII of the Rehabilitation Act. It was the first Federal legislation to specifically authorize funding for services needed by people with such severe disabilities that they do not presently have the potential for employment. It permits services to be provided to those presently without employment potential if they may benefit from vocational rehabilitation services (authorized under Title I, Part A) which will improve their ability to engage in employment or to live and function independently in their families or communities. Part A of Title VII authorizes payments for independent living services that are provided under approved State Plans. Part B authorizes a grant program for the establishment and operation of independent living centers that offer, among other services, the services funded under Part A. Part C authorizes funds to provide independent living services for elderly blind individuals.

Funding for independent living services under Title VII is very limited when compared to Medicaid (Title XIX of the Social Security Act) funding for institutional care for people with severe disabilities. If community-based independent living is to become a realistic goal for Americans with severe disabilities, the institutional bias within Medicaid and other programs funded

under the Social Security Act must be replaced by a preference for community-based services.

1. Congress should require the agency in each State designated to administer Title VII, Part A of the Rehabilitation Act to allocate no less than 50% of available funds to purchase services from independent living centers that meet the standards approved by the National Council on the Handicapped. No more than 10% of available funds should be used for administrative purposes. The remaining funds should be used at the discretion of the administering agency in any way that assists people with severe disabilities to achieve independence and productivity in their communities.

Currently States are required to provide assurances in their State Plans that no less than 20% of the funds received by a State under Part A are used to make grants to local public agencies and private nonprofit organizations for the conduct of independent living services (unless a waiver of this requirement is obtained from the Commissioner of the Rehabilitation Services Administration). The Council recommends that this percentage be increased to 50% to assure that funding for independent living services is available to and provided by agencies established and operated for this purpose under Title VII, Part B. Such funding for services should be authorized only for independent living centers that comply with the standards approved by the Council.

Coordinated services are essential to the ability of a person with a severe disability to live in the community. Therefore, the Council recommends that States applying for Part A funds be required to submit a plan for the coordinated delivery of services, including personal assistance services (attendants, readers, interpreters, and advocates for mentally retarded persons); and accessible housing and transportation; and for State-wide information and referral services for all people with

disabilities and their families. Administrative expenses for arranging services should be strictly limited to 10% of these funds.

The Council recommends that funding for Part A be continued as a means of ensuring that community-based services are made available to persons with severe disabilities. Its implementation should include requirements that independent living facilities and services comply with standards approved by the Council for program administration, service delivery, and program evaluation.

2. Congress should provide core funding under Title VII, Part B of the Rehabilitation Act, for independent living centers that meet the standards approved by the National Council on the Handicapped. Such centers should be allowed to apply and compete for this funding on an equal basis with State vocational rehabilitation agencies.

Community-based, consumer-controlled independent living centers were created to assist persons with severe disabilities to increase their level of independence. As defined in Title VII Part B of the Rehabilitation Act, these centers must significantly involve disabled persons in policy direction and management, and must offer a combination of independent living services. Part B of Title VII, which funds over 150 of these centers nationwide, should be used as an ongoing source of funding to support the start-up of new centers and to provide core support for established centers, whether or not these centers have received Title VII funding in the past. At least 20% of Part B funds should be used to support the establishment of new independent living programs, with an emphasis on rural and other underserved areas. The remaining available funds should be

used for core support of established centers.

The standards adopted by the National Council in 1985 for evaluating independent living centers should be enforced as a prerequisite for the distribution of funds. New centers which do not meet the standards at the time they apply for Federal funding should be required to follow a pre-application process and have a plan to meet the standards before receiving Federal funding. In addition, independent living centers should be strongly encouraged to obtain funding from other public and private sources. All centers should include representatives of the business community on their boards of directors. A mechanism should be established to provide incentives for States to match Federal efforts for independent living centers.

The Council wishes to note that in requiring independent living centers to be consumer-controlled, it defines "consumer" as including persons with all types of disabilities. It believes that those with mental retardation or a history of mental illness, for example, can serve a vital role as consumer members of boards or in other responsible positions.

3. Congress should require the Health Care Financing Administration to study the institutional bias within its programs for persons with disabilities and to develop appropriate measures for eliminating such biases. The criteria should be developed in consultation with the National Council on the Handicapped and be reported in hearings before Congress within one year from the date of enactment of this requirement.

An extraordinary amount of the Medicaid funds administered by the Health Care Financing Administration (HCFA) is spent on nursing homes and other long-term institutions that primarily

provide custodial maintenance for disabled individuals. The Council believes that strictly maintenance-oriented institutional programming is indefensible and unnecessary. Wherever possible, institutions should be transitional and foster independence. The majority of available funding should be directed toward assisting all individuals with severe disabilities to achieve self-direction and independence to the maximum of their potential, in the most dignified and least restrictive enviornment.

The Council recommends that Congress require HCFA to develop, posthaste in consultation with the National Council on the Handicapped, criteria to be used to determine to what extent Medicaid and other programs administered by HCFA promote community-based services and discourage placements in institutions. Programs that serve people with disabilities should be assessed using these criteria, and the resulting report should be used as a basis for making fundamental changes in the management and structure of these programs. The Council recommends that the Congress hold hearings within one year of the enactment of this requirement to review HCFA findings and plans for action.

The evaluation criteria should include a focus on the following topics:

- Comprehensive personal assistant services, including long-term, short-term (respite), and emergency attendants, readers, interpreters, and advocates for mentally retarded people.

- Case management assistance for independent living, including transition services from the hospital to the home, institution to community, and from parents' home to independence in the community; and assistance in

equipment selection and maintenance, and in locating sources for other independent living support services.

- o Family support and consumer education services, including financial and personal counseling and training in self-directed and family-provided home care, including the use of equipment and medication, and independent living skills training.

- o Habilitative and rehabilitative training, including prevocational services.

- o Comprehensive medical insurance for disabled persons who are unable to obtain adequate insurance through their employers or who are ineligible for other Federal medical benefits.

4. Congress should amend the Internal Revenue Code to establish a tax credit for taxpayers with disabilities who incur unreimbursed expenses directly related to independent living, employment, and efforts to secure employment, including personal assistant services, special transportation, assistive devices, and other support services.

This recommendation is made as a partial means of removing the disincentives to work which are inherent in the Social Security system. While certain tax deductions are currently allowable under a medical categorization, the regulations are unclear regarding nonmedical, disability-related services which enable the individual to work or engage in productive activity. Such expenses, up to a reasonable amount for each type of expense, should be made deductible.

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